

Measuring quality of life – theoretical background

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Abstract

Patient-centred medicine has come out of the increasing importance of patients’ voices in disease management. As part of this, health-related quality of life (HR-QoL) has become an important part of assessing treatment outcome and the quality of patient management. In this article, I discuss health as one of the determinants of a good quality of life and how to interpret and present HR-QoL measures and thereby place them in a clinical context. Key issues covered include the theoretical HR-QoL models underlying HR-QoL measures, how the measures are constructed, how they work, and how to interpret the scores they generate.

Socrates: . . . And I should like to know whether I may say the same of another proposition – that not life, but a good life, is to be chiefly valued?

Crito: Yes, that also remains.

– *From Crito; The collected works of Plato*



Humans have always desired to live a good life, that is, to enjoy a high quality of life (QoL), although what this means is very different for each of us. As illustrated by the QoL index, developed by *The Economist Intelligence Unit*,¹ QoL is complex and encompasses many aspects of life. The index includes material well-being, health, political stability and security, family life, community life, climate and geography, job security, political freedom and gender equality (Figure 1). In this article, I discuss only one of these determinants – health – in other words, the application of QoL to medicine, often referred to as health-related QoL (HR-QoL). I also present a few QoL models relevant to HR-QoL and describe the main ways to measure HR-QoL.

Health-related quality of life

The World Health Organization defines health as “a state of complete physical, mental and social

well-being, and not merely the absence of disease or infirmity”.²

Although this definition does not include HR-QoL, it clearly includes different aspects of well-being as principal attributes of full health. In the context of this definition of health, the notions of HR-QoL and health status are closely interrelated and should not be considered separate.

According to the International Society for Pharmacoeconomics and Outcomes Research, HR-QoL is “a broad theoretical construct developed to explain and organise measures concerned with the evaluation of health status, attitudes, values, and perceived levels of satisfaction and general well-being with respect to either specific health conditions or life as a whole from the individual perspective”.³ More specific examples of QoL aspects (also known as “dimensions”) are described by Fayers and Machin:⁴

- General health with a focus on functional status both physical and emotional;
- Checklists of symptoms;
- Daily living activities;
- Personal well-being;
- Sexual functioning; and
- Impact of illness on social, emotional, and family functioning.

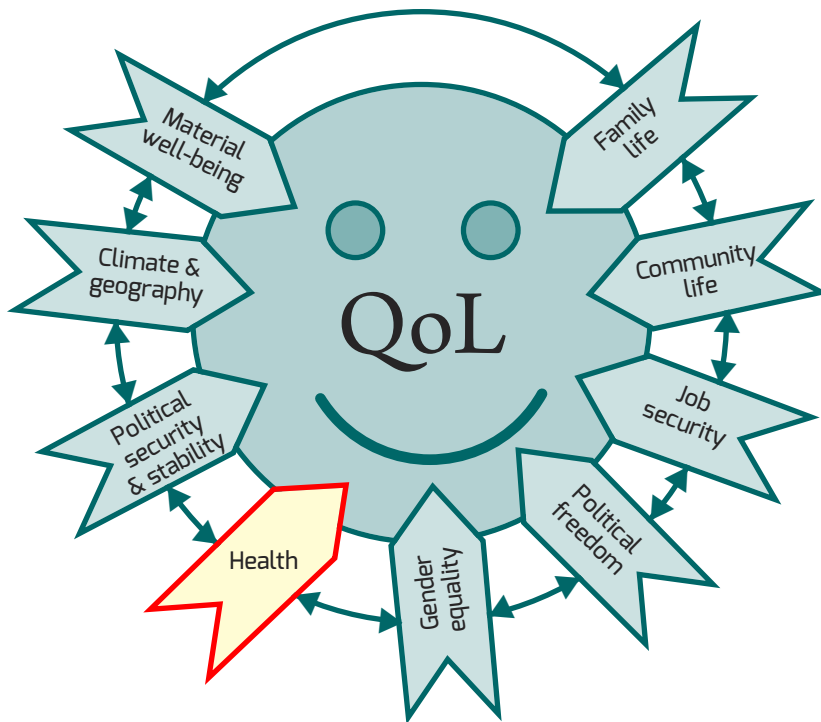


Figure 1. QoL – index developed by The Economist Intelligence Unit.

Modified from Koltowska-Hägström et al. 2009.¹⁷

The authors, therefore, conclude that HR-QoL is a multidimensional construct. They also emphasise that subjectivity is a basic and unquestionable feature of HR-QoL so that it can be evaluated only by patients themselves. The only exceptions to this are for patients who are incapable of providing information, for example, small children, patients with communication problems, or patients intellectually incapable of effectively responding. For such cases, proxy measures are acceptable.⁵

QoL models

A variety of HR-QoL models have been proposed and are the basis for various HR-QoL

measures. One of the first models was developed by Ware,⁶ who specified three generic health concepts: physical health, mental health, and general health, which he placed on a continuum (Figure 2). Briefly, physical conditions are closely linked to physical symptoms. These lead to physical limitations and reduced well-being. Similarly, mental conditions relate to mental symptoms and consequently cause psychological distress and poor well-being. Both physical and mental conditions can severely impair perceived general health. This model underlies the SF-36 (36-Item Short Form Survey),⁴ one of the most commonly used HR-QoL measures.

Another continuum-based model of QoL was

developed by Wilson and Cleary⁷ who highlighted increasing complexity when moving from biological and physiological factors (the lowest level) through symptoms, functioning, and general health perceptions to overall QoL (the highest level) (Figure 3). Throughout different levels, their model also incorporates relationships and other factors, such as characteristics of the individual and the environment and non-medical factors.

In 1965, Nagi introduced the first disablement model including active pathology, impairment, functional limitation, and disability (Figure 4), thus starting a new family of models. In this model, impairment is a structural abnormality at an anatomical level (cells, tissues, organs); functional limitation indicates a difficulty in performing activities; and disability is categorised as physical, mental, social, or emotional and covers the ability of a person to fulfilling role in life. Nagi’s main contribution to patient-centred medicine was to move the concept of disability away from pure physical dysfunctions to interactions between the patients and their environment. More recent disablement models, such as those of the National Center for Medical Rehabilitation Research Disablement Model and the World Health Organization International Classification of Functioning Model, are rooted in Nagi’s concept.⁸

Calman’s expectation model⁹ assumes that QoL reflects the distance between individual’s present experience and expectations (Figure 5). In this model, a smaller gap corresponds to a better QoL, and QoL can be enhanced by improving the current situation, for example by treating disease or modifying expectations. The Evaluation of Individual Quality of Life (SEIQoL) and the Patient Generated Index are

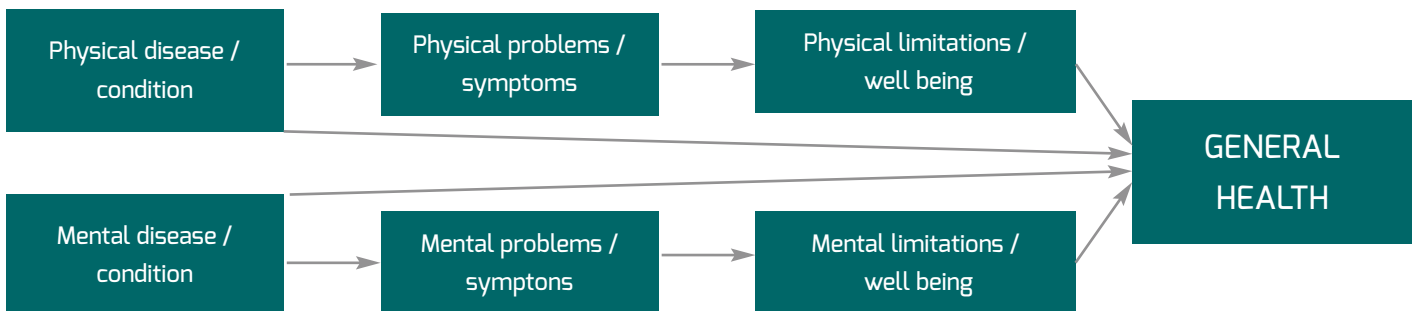


Figure 2. HR-QoL model proposed by J. R. Ware

Modified from Ware et al. 1995.⁶

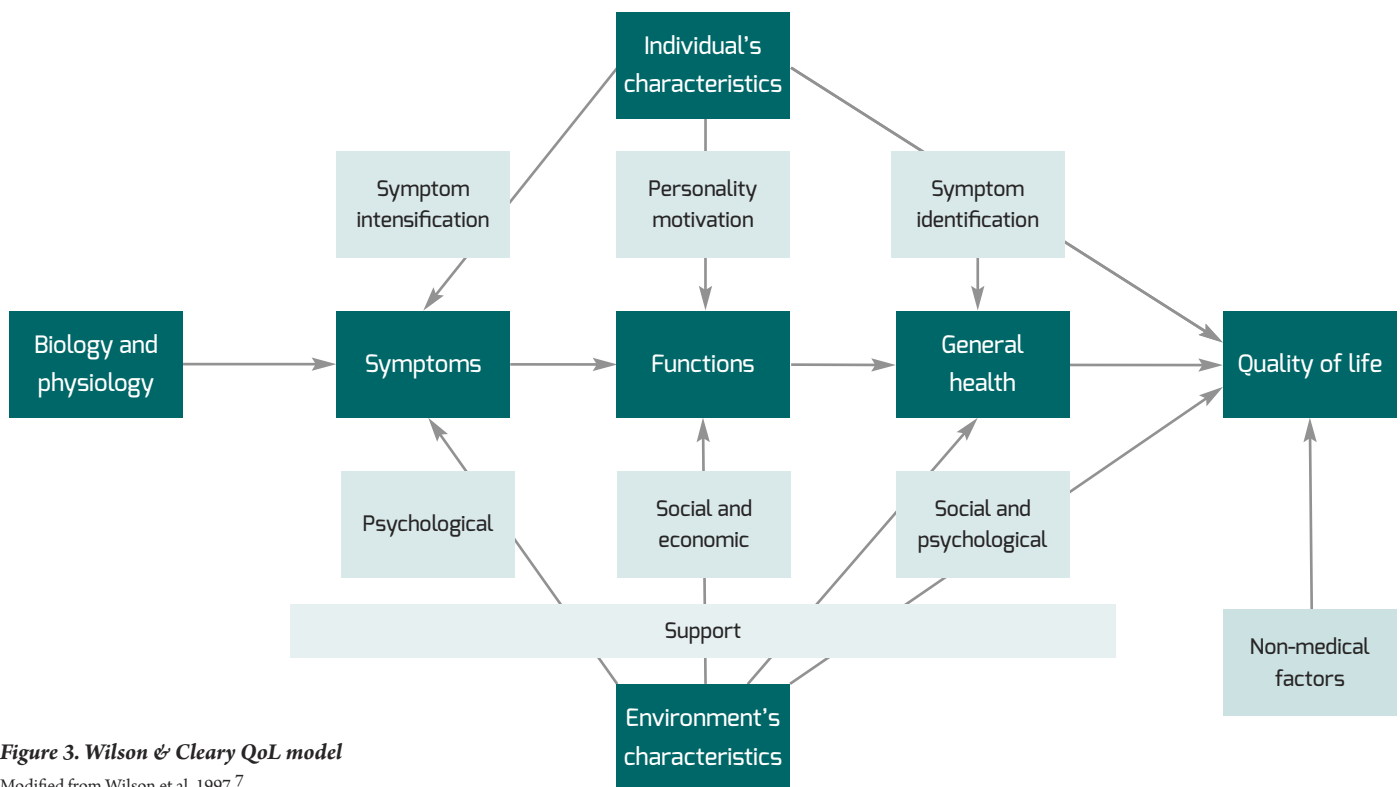


Figure 3. Wilson & Cleary QoL model

Modified from Wilson et al. 1997.⁷

based on Calman's model.⁴

A similar rationale applies to the need-based model, in which QoL depends on the personal capacity to satisfy human needs. In this model, poor health interferes adversely with satisfying needs, and thus has a negative impact on QoL. Nevertheless, this model assumes that as long as the primary needs are fulfilled, for example, by compensation mechanisms, QoL remains unchanged.¹⁰ Examples of need-based measures are the QoL-AGHDA (QoL-Assessment of Growth Hormone Deficiency in Adults) and the QLDS (QoL in Depression Scale).¹¹

Item structure, scales, and scores

Item structure – index and profile

HR-QoL measures are built from items (questions or statements) and can contain just one (single-item measure) or several (multi-item measure). The items in multi-item measures can constitute one dimension (unidimensional) or more (multidimensional). Depending on the item structure, HR-QoL measures produce two types of scores: an index or a profile. Single-item measures generate an index (a single number), whereas multi-item measures generate a profile or an index. Profiles are represented by a set of scores for each measured dimension (subscale).

They provide more detailed information about the characteristics of HR-QoL and enable better understanding of the problems respondents are facing.⁴ Therefore, profiles are suitable for clinical practice, although they may not be able to capture an overall change in HR-QoL (magnitude and direction). The NHP (Nottingham Health Profile) is a good example of a multidimensional measure: it includes sleep, pain, emotional reactions, social isolation, physical mobility and energy level.¹² For some profiles, a simple sum of dimension scores is accepted, although their accuracy is questionable because the calculation assumes equal importance of each dimension, which is often not the case. This problem can be overcome by applying weights, which are relative values for each dimension (or even item). Derived in this way, a

single aggregated score is believed to be robust and appropriate.⁵ For NHP, an index can be computed based on weighted or unweighted dimension scores.¹³

Scales and scores

Information is collected in different ways by HR-QoL measures. Many but not all are based on an ordinal scale. The simplest are dichotomous variables describing health status (e.g. non-diseased/diseased) or by a yes/no answer for specific problems. This is often used to construct need-based measures. For these, the score can be generated by simply summing up the number of "yes" answers, in other words, the number of recognised problems. Therefore, a higher numerical score denotes poorer HR-QoL, and a decrease in the score indicates improve-

When interpreting and writing up data generated with a Likert's scale, its ordinal properties and its subjectivity must be considered.

It is also critical to understand how the choices are coded, that is, whether a higher score indicates better or worse HR-QoL and whether an increase indicates improvement or deterioration. Finally, when comparing results originating from different HR-QoL measures, it is important to check whether working scores or scale scores are used.

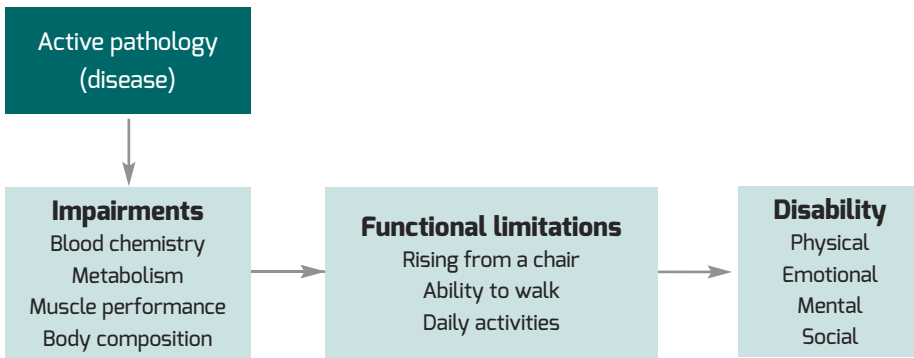


Figure 4. Nagi's disablement model

Modified from Woodhouse et al. 2006.¹⁸

ment.¹² Such a descriptive classification distinguishes between different categories and orders them hierarchically.

Likert scale

The most frequently used scales for measuring QoL are ratings like Likert's scale¹⁴ and the visual analogue scale (VAS). Likert introduced his scale in 1932 to measure social attitudes in the US. The items he included, particularly in the "Negro scale", are nowadays considered shocking, but the way he proposed to collect information is widely used. Likert's scale contains one or more items (statements), each linked to several choices, usually ordered from the lowest to the highest level, for example, worst/not important at all/never/completely disagree and best/extremely important/always/fully agree, with intermediate choices in between (Figure 6). Although five options are usually used for most items, the

number can vary from three to nine. An odd number of choices is recommended to allow for a "neutral" choice. For analysis, the choices are coded as sequential numbers, for example, from 1 for worst to 5 for best. These numbers are summed to generate a single score (index). Sometimes the raw (working) score is standardised to a scale 0 of 100 to facilitate comparisons between different measures. Such a standardised score is called the "scale score", and the standardisation to a 100-point scale is referred to as "the standard scoring method".⁴ Because the scale is ordinal, it does not have a well-defined unit of measurement, and it can only indicate a direction of a change but not its magnitude. For example, the distance from "not important at all" (1) to "little important" (2) is not necessarily the same as between "little important" (2) and "important" (3)". In other words, the change from (1) to (2) does not need to be equal to the

change from (2) to (3).⁵ When interpreting and writing up data generated by a Likert's scale, its ordinal properties and its subjectivity must be considered. It is also critical to understand how the choices are coded, that is, whether a higher score indicates better or worse HR-QoL and whether an increase indicates improvement or deterioration. Finally, when comparing results originating from different HR-QoL measures, it is important to check whether working scores or scale scores are used.

Visual analogue score

The linear analogue self-assessment, now referred to as the VAS, was first used by Priestman and Baum to measure HR-QoL in patients with breast cancer.¹⁵ It consists of a 100-mm horizontal or vertical line on which a respondent places a mark in response to a question (Figure 7). A VAS is anchored at one end by the lowest choice (e.g. worst possible/never/not important at all) and the other by the highest choice (e.g. best possible/always/extremely important). The score is computed as the measured distance from the left end to the respondent's mark. Thus, the VAS is a continuous scale that generates a single score.¹⁶

Conclusion

Patient-centred medicine has come out of the increasing importance of patients' voices in disease management. As part of this, HR-QoL has become an important part of assessing treatment outcome and the quality of patient management. Understanding the theoretical background and basic rules governing HR-QoL research is essential for being able to correctly interpret and present HR-QoL data. In other words, one must understand what the numbers mean and remember that for HR-QoL, 2 + 2 is not always 4 and 2 is sometimes more (better) than 3!

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Conflicts of interest

The author declares no conflicts of interest.

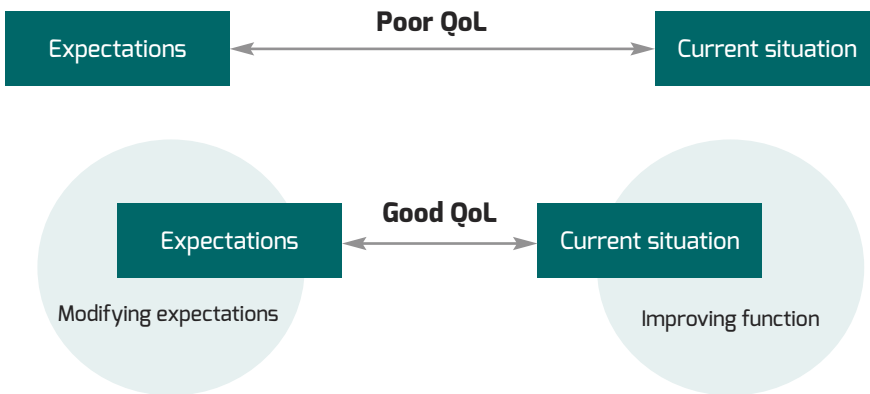


Figure 5. Calman's QoL expectation model

Modified from Calman et al. 1984.⁹

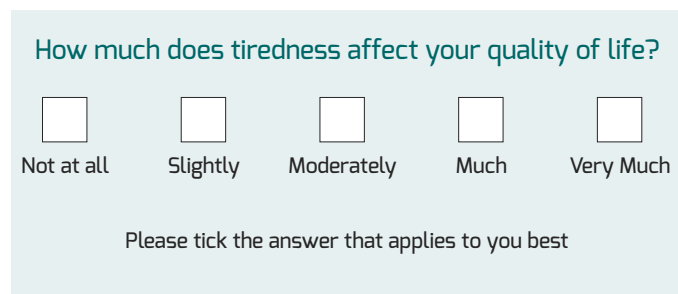


Figure 6. Example of a Likert scale

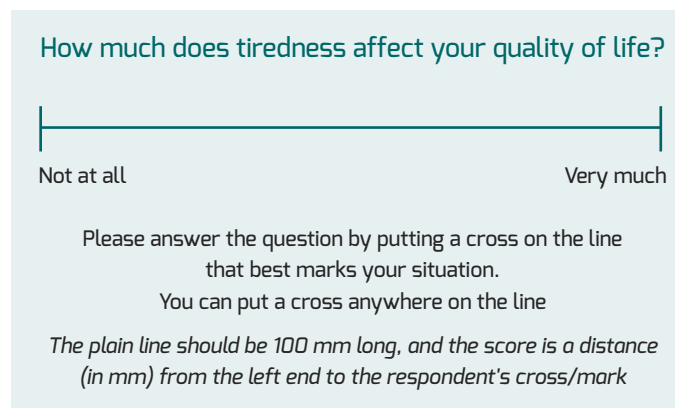


Figure 7. Example of a visual analogue scale (VAS)

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Maria Kołtowska-Hägström, MD, PhD, a co-owner of Proper Medical Writing, the first Polish medical writing agency, earned her PhD at Uppsala University (2008) based on the dissertation “Quality of life in adult patients with growth hormone deficiency; bridging the gap between clinical evaluation and health economic assessment”. Maria is author of over 70 peer-reviewed publications, many of them relating to research on patient-reported outcomes. She is also a member of the European Association of Scientific Editors, European Society of Endocrinology, and Growth Hormone Research Society; reviewer for a number of journals; and an Associate Editor for *BMC Endocrine Disorders*. A longtime EMWA member, Maria is a section editor for *Medical Writing*, workshop leader, and Chair of an Expert Seminar Series.



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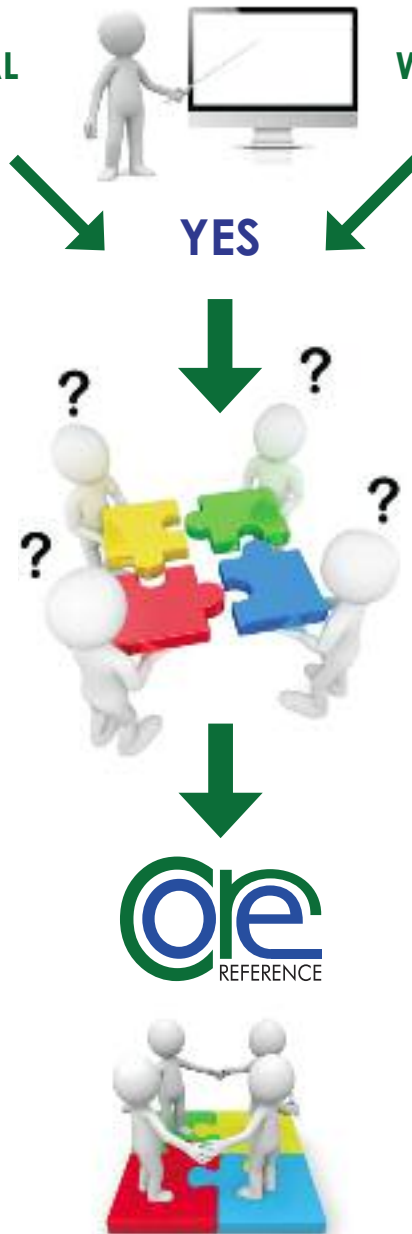
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